

BLOOD HEALTH



Read why Hillary McKibbin believes everyone deserves a life-saving bone marrow transplant.



Is Canada Prepared to Cure Rare Blood Disorders?



Durhane Wong-Rieger
President & CEO,
Canadian Organization for Rare Disorders

Fifty years ago, three rare blood disorders experienced therapeutic breakthroughs that transformed once crippling and fatal diseases into manageable chronic conditions.

- In 1967, hydroxyurea was approved, thereby reducing the risk of crises in sickle cell disease.
- In 1968, deferoxamine became available, reducing the risk of organ damage for thalassemia patients with blood transfusions.
- In 1971, freeze-dried clotting factors became available for hemophilia patients, freeing them from in-hospital plasmapheresis.

In ensuing years, therapeutic advances have improved the lives of those with other anemias, myeloproliferative neoplasms, thrombocytopenias, and leukemia.

Today, advances in organ, bone marrow, and stem cell transplant have increased their feasibility, safety, and durability. But accessibility is limited by a lack of investment in technologies, facilities, and clinicians.

Modified cell and gene therapies demonstrate long-term benefits (five years plus) with no disease or symptom recurrence. But they come with high up-front costs.

In Canada, no multi-stakeholder consultations are taking place. Gene therapies aren't considered in the proposed National Pharmacare. Even worse, stringent — cost-effectiveness — thresholds proposed in the new Patented Medicine Prices Review Board regulations will automatically exclude these therapies based on their high entry costs, despite future decades of cost savings.

When will Canadian policy makers step up to the challenge of providing innovative access solutions to these curative therapies to all patients, including those with rare blood disorders? ♦

Senior Publisher: **Jessica Golyatov** Business Developer: **Brian von Allmen** Country Manager: **Jacob Weingarten** Content Strategy Manager: **Margot Thomas** Production Manager: **Calli Eliopoulos** Lead Designer: **Yeganeh Ghasemi** Web Editor: **Kaleigh McLelland** Contributors: **Gavin Davidson, Randi Druzin, D.F. McCourt, Anne Pappmehl, Dr. Fabio Rossi, Alicia Talarico, Durhane Wong-Rieger, Dr. Peter Zandstra** Photo Credits: **Frank Lennon**
Cover photo: **McKibbin Family** All images are from Getty Images unless otherwise credited. This section was created by Mediaplanet and did not involve Maclean's magazine or its editorial departments. Send all inquiries to ca.editorial@mediaplanet.com.

Our blood holds
IMPORTANT
CLUES to
our health.



Hear from hockey legends, **Paul Henderson** and **Kerry Fraser** about how a simple test can put you ahead of the game.

Learn more on page 5



Join Hillary's movement at startwithhillary.ca.

Hundreds of Patients like Hillary Need a Stem Cell Donor

lable bleeding. If the six-year-old's condition worsens, she'll need a stem cell transplant.

Unwilling to take any chances at finding a stem cell match, Hillary's mother, Kelly McKibbin, organized two cheek-swabbing events in Ottawa and encouraged young men between the ages of 17 and 35 to attend — a donor demographic that improves patient outcomes.

Record-breaking donor turn-out

More than 630 individuals attended the first event in June — so many that organizers ran out of swab kits. Another 450 people ordered the kits online, 250 attended the second event in July, and three more large events are being held this fall.

"It was quite moving," says Kelly. "Young men, parents, and students showed up in droves with tears in their eyes, saying, 'You

need help? No problem.'" These new donors' information gets added to the Canadian Blood Services Stem Cell Registry.

As the family's #StartWithHillary campaign continues to inspire Canadians across the country and all over the world, optimal donors — young males — are encouraged to join the registry. At any given time, Canadian Blood Services is searching for donors on behalf of hundreds of patients from diverse ancestral backgrounds in need of a stem cell donor.

"We want to find a match and help the world while we're at it," says Kelly. "We want to raise awareness and inspire people to help Hillary, but also the thousands like her around the world in need of a donor." ♦

Randi Druzin

When Hillary McKibbin's blood test results came in, a lab technologist called her parents and told them to get her to the hospital immediately — she needed a blood transfusion.

Hillary was diagnosed with a rare blood disease called idiopathic aplastic anemia, a condition in which the body doesn't produce enough new blood cells. It causes fatigue, an increased risk of infection, and uncontrol-

Stem Cell Donors Could Be Someone's Hope for Life

Every year, hundreds of Canadian patients need life-saving stem cell transplants, and most rely on the generosity of an unrelated donor. Found primarily in umbilical cord blood, peripheral circulating blood, and bone marrow; blood-forming stem cells are used to treat more than 80 diseases and disorders, such as leukemia, lymphoma, aplastic anemia, and sickle cell disease.

To significantly increase the odds of finding a matching stem cell donor for patients, the Canadian Blood Services Stem Cell Registry — the public registry responsible for recruiting and finding healthy, committed volunteer donors — belongs to an international network of registries to match potential donors and recipients around the world. For every patient who finds a match among their family, three will rely on a total stranger's generous donation of life-saving stem cells. With almost 450,000 registrants and access to more than 35 million potential stem cell donors on this network, the odds of finding a match are much, much higher.

"If you donate cord blood or join the stem cell registry, you may save a life," says Dr. Heidi Elmoazzen, Director of Stem Cells at Canadian Blood Services. It's that simple. Yet, about half the registrants contacted to launch the actual donation process decline to proceed with the donation — a potentially devastating experience for the patient. This is why registrants are often reminded that joining the registry is a long-term commitment — it could be months or even years before they may be called to donate.

Seeking optimal, diverse donors

Patients are more likely to find a donor from within their own ancestral group. Also, patients of diverse ethnic or mixed-race backgrounds face a much steeper hill when searching for a stem cell match. This is why the stem cell registry specifically targets potential donors from diverse ethnic backgrounds who are also optimal donors — males aged 17 to 35.

Donating cord blood — the blood that remains in the umbilical cord and placenta after the birth of a healthy baby — is another way to help patients. Canadian Blood Services' Cord Blood Bank launched in 2013 to provide expectant mothers the opportunity to donate to a national public cord blood bank at four hospital collection sites in Ottawa, Brampton, Edmonton, and Vancouver.

Join the registry; donate cord blood

Joining the Canadian Blood Services Stem Cell Registry involves a simple cheek swab and the understanding that this could be a long-term commitment. For pregnant moms living in a city with a designated cord blood collection hospital, you and your tiny hero could save lives by joining Canada's Lifeline. ♦

Randi Druzin

Register to join the registry or donate cord blood at blood.ca.



Dr. Heidi Elmoazzen
Director, Stem Cells,
Canadian Blood Services



Stem Cell Therapy Is Saving Lives, but Not Everything Using That Name Is Legitimate

The promise of stem cells has captured the imagination of doctors, scientists, and the public. By using our bodies' own stock of undifferentiated cells to repair or grow new tissue, there's a possibility to treat all kinds of diseases and conditions that were previously intractable.

Lives are already being saved by stem cells

As bone marrow transplants, stem cells have been used to treat leukemia and other blood conditions for decades. "Recently, the use of hematopoietic stem cells for the treatment of multiple sclerosis has demonstrated incredible improvements for patients," says Dr. Denis Claude Roy, a hematologist at the Maisonneuve-Rosemont Hospital and CEO at CellCAN, a Canadian regenerative medicine and cell therapy network that promotes clinical research and development.

Illegitimate cell therapies

The potential of stem cell therapies has created a growing market for unscrupulous clinics to market purported stem cell-based therapies. This is very worrisome, as these treatments haven't shown efficacy and safety data. In Canada, all legitimate therapies are offered by **qualified physicians specializing in disease management** in a hospital setting, with follow-up care. "Before receiving treatment outside of a recognized hospital, please talk to your treating physician," recommends Dr. Roy. ♦

D.F. McCourt

Sponsored by



Is your treatment legitimate?

- 1 Is the treatment offered as a "one size fits all?"
- 2 Are you being **charged money** to get this treatment?

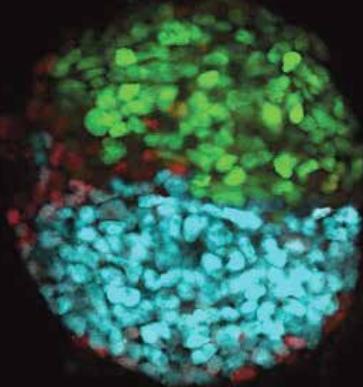
- 3 Is the clinic providing **patient testimonials** almost exclusively to demonstrate the effectiveness of the treatment?

» If you answered yes to one or more of these questions, then, most likely, that clinic is offering you an unproven treatment.

Talk to your doctor.

Read the full article online at healthinsight.ca.

Fast Forward the Future



Dr. Peter Zandstra, FRSC, PEng

Canada Research Chair in Stem Cell Engineering, Director & Professor, School of Biomedical Engineering & Michael Smith Laboratories



Dr. Fabio Rossi M.D.

Director, The Biomedical Research Centre, UBC Director of Research, School of Biomedical Engineering Scientific Director, BC Regenerative Medicine Initiative

Stem cells enable marriage between regenerative medicine and biomedical engineering.

Over the past decade, our understanding of how stem cells work has increased tremendously, opening up the possibility of cures to devastating diseases. However, to turn this promise into real applications, we need to overcome one important hurdle: how to convince stem cells to do what we need them to do in the right place at the right time.

Enter biomedical engineering, a field with expertise that can direct cell behaviour, either by engineering new functions

within the cells themselves, or by building devices in which biology and technology interact in unprecedented ways.

Engineering cells requires an understanding of how they work. Understanding the mechanisms that make specific cells tick will allow us to rearrange them in favourable ways and to control cell behaviour for clinical applications.

The best example of this is the modification of T-cells to recognize and kill tumour cells, commonly known as chimeric antigen receptor (CAR) T-cells. While CAR T-cells are revolutionising cancer therapy, other

powerful approaches, such as cells that prevent immune cell misbehaviour, or hybrids devices incorporating engineered cells and manufactured components to treat diseases such as Type 1 diabetes, are a source of hope for millions of people.

Excitingly, all of this and more is going on in BC, and is helping build a foundation for biotechnology leadership in Canada and across the world. Partnerships between organizations such as the British Columbia Regenerative Medicine (BCRegMed) initiative, the UBC School of Biomedical Engineering, and others, such as the

Creative Destruction Lab-West, are creating an environment that facilitates the rapid deployment of new discoveries, and promise that there's much more to look forward to in the near future, both in terms of medical advances and economic growth. ♦

Sponsored by

BCREGMED

THE UNIVERSITY OF BRITISH COLUMBIA
School of Biomedical Engineering
Faculties of Applied Science and Medicine

How LLSC Supports Canadians at Every Stage of Their Blood Cancer Experience



Alicia Talarico
President, LLSC

The Leukemia and Lymphoma Society of Canada (LLSC) is the single largest health agency in the country, dedicated to all blood cancers.

We fund life-saving blood cancer research across the country, and provide information and support services at no charge to people affected by the disease. To date, we've invested more than \$40 million in research to better understand the cause of blood cancers,

develop better therapies, and improve the quality of life for those impacted.

I'm extremely proud of the important work our staff and volunteers have done to support more than 138,000 Canadians and their families throughout their cancer experience.

I often hear from the public that they're not sure how to get involved in their community. At LLSC, every voice, every action, and every dollar we raise counts and brings us closer to a cure.

Because of our donors, we've built a robust paediatric cancer program and we continue to enhance many other services to help support Canadians at every stage of their blood cancer experience. Because of our volunteers, we continue to offer our peer-to-peer program that

connects those diagnosed with a blood cancer with someone who has been through it before.

I'm continually inspired by our community of donors and volunteers who answer the call to give again and again. Their commitment to our mission makes us that much stronger in our pursuit to cure all blood cancers and support those affected by them. ♡

Alicia Talarico

To learn more about making a difference in your community, visit llscanada.org.

Supported by



Ensuring Timely Intervention for BMT Complications

Bone marrow transplantation (BMT) saves lives and has many benefits. But it's important to be aware of the potentially life-threatening complications.

One of those is veno-occlusive disease (VOD), also known as sinusoidal obstruction syndrome (SOS) of the liver. SOS occurs when the small blood vessels inside and leading to the liver become blocked. "Though this happens on a very small scale, it can become widespread over time, causing lasting and even permanent damage," says Dr. Arjun Law, Staff Physician at the Hans Messner Allogeneic BMT Program at Princess Margaret Cancer Centre. Symptoms can include jaundice, liver tenderness, liver enlargement, and even liver failure.

BMT, also known as HSCT (hematopoietic stem cell transplant) are commonly used to treat patients with leukemia. To prevent the body from rejecting the new bone marrow or stem cells, patients are prepared with a conditioning regimen of chemotherapy, radiation, and immune-suppressing drugs to wipe out their existing immune system.

With no immune system to protect them, and the new bone marrow or stem cells not kicking in for two to four weeks post-transplant, patients are very vulnerable during this time to complications like SOS. "Fortunately, thanks to advances in the field and therapies tailored to the individual patient, incidences of SOS have decreased in the last decade," says Dr. Jonas Mattsson, Gloria and Seymour Epstein Chair in Cell Therapy and Transplantation and Director of the Hans Messner Allogeneic Transplant Program.

Signs and symptoms not always obvious

"Unfortunately, SOS is not something you can diagnose visually or with a test, so you just have to keep it in the back of your mind as a potential complication," says Dr. Law. Some early clinical signs are weight gain from fluid retention and mild hepatic (liver) dysfunction. "Picking up on these symptoms early gives us more time to intervene and get better outcomes," says Dr. Law.

Dr. Mattsson agrees, stressing that, "it's extremely important to see your patients every day and carefully evaluate them for appearance, because a weight increase may not be significant, or sometimes you won't see things in a lab that you will see in a patient; so bedside treatment has a critical role in bone marrow transplantation."

From a nursing perspective, "Education is paramount because the nurses are with the patient 24 hours a day," says Zoe Evans, Nurse Practitioner at the Hans Messner Allogeneic BMT Program. "If they know what to look for, they act as our eyes and ears to ensure we can intervene as soon as possible." ♡

"Though this happens on a very small scale, it can become widespread over time, causing lasting and even permanent damage"

Anne Pappmehl



Dr. Jonas Mattsson
Director, Hans Messner Allogeneic BMT Program



Dr. Arjun Law
Staff Physician, Hans Messner Allogeneic BMT Program



Zoe Evans
Nurse Practitioner, Hans Messner Allogeneic BMT Program

This article was made possible with support from Jazz Pharmaceutical.

My Blood, My Health – a Simple Test Can Put You Ahead of the Game

As Canadians, we could say that hockey is in our blood. But hockey legends Paul Henderson and Kerry Fraser understand all too well that blood also holds clues to our health. A blood test in 2009 revealed that Henderson had chronic lymphocytic leukemia and in 2017 Fraser found out he had essential thrombocythemia, a rare blood cancer.

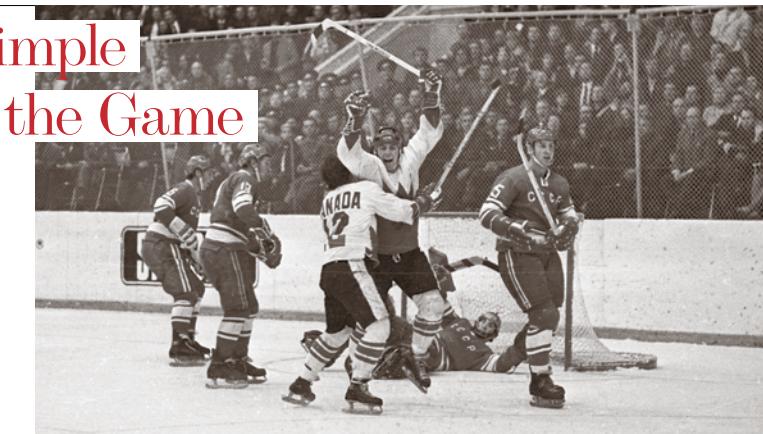
“Something didn’t feel right with my body and I had to make a call – thankfully I made the right one and called my doctor,” says Fraser, a broadcaster and former National Hockey League senior referee.

Fraser and Canada’s Sports Hall of Famer Henderson have teamed up with Heal Canada, a collaborative patient advocacy

and education organization, and Novartis Pharmaceuticals Canada Inc. to raise awareness about the need for Canadians to speak up when something doesn’t feel right with their bodies.

“A simple blood test could help you find out what’s going on with your body.”

Symptoms of blood cancers can be deceptive and can sometimes be mistaken for a bad cold or flu, or there may just be a general feeling of being unwell. The complete blood count (CBC) test can help detect an underlying condition.



Henderson celebrating the winning goal for Team Canada in the '72 Summit Series. Taken by Frank Lennon, the photo has been called “one of the 10 images that changed Canada.”

“A simple blood test could help you find out what’s going on with your body. It could be nothing, but if it isn’t, you need to form a solid game plan with your health team as soon as possible,” says Fraser. ♦

More information on how to play to win when it comes to deciphering clues to your health can be found at mybloodmyhealth.ca.

Canadian MPN Research Foundation Aims to Find a Cure for Progressive Blood Cancers

When someone says blood cancer, you may immediately think of leukemia, but there are many types of blood cancer that aren’t as well-known. For those living with myeloproliferative neoplasms (MPNs), these serious cancers are very real and often incurable.

MPNs are progressive blood cancers in which the bone marrow typically overproduces one or more types of blood cell. The three most common classical MPNs are polycythemia vera, essential thrombocythemia, and myelofibrosis.

With stem cell research and the discovery of key gene markers, there have been significant advances in the diagnosis, understanding, and treatment of MPNs, but there are still no known cures for most of these cancers.

The Canadian MPN Research Foundation is on a mission to change that. Founded in 2018 by Executive Director Cheryl Petruk, the organization has a single goal: to stimulate and fund original and ongoing research in pursuit of new treatments and eventually a cure for MPNs. Cheryl became an advocate for the MPN community when she began caring for her late husband.

The dedicated members of the board each have very personal and committed ties to the foundation’s mission. They seek to support MPN research projects in centres across Canada, including at the Elizabeth and Tony Comper MPN Program at Toronto’s Princess Margaret Cancer Centre, which is exploring novel treatment, models of care, and education strategies.



Dr. Vikas Gupta

Director, Elizabeth & Tony Comper MPN Program, Princess Margaret Cancer Centre
Professor, University of Toronto

“It’s unimaginably devastating to be diagnosed with an incurable blood cancer.”

“It’s unimaginably devastating to be diagnosed with an incurable blood cancer,” says Dr. Vikas Gupta, who leads the clinical research team. Patients with MPNs have a heavy symptom burden which affects their day-to-day life. Several of the complications related to MPNs such as thrombosis, are preventable. “That’s why we’re working so hard to make significant strides in our understanding and treatment of these progressive cancers,” says Dr. Gupta. “The funding we’ve received so far has helped us start our journey, but we have a long way to go. With the support from funding partners, we’ll continue to work hard towards our goal of finding a cure.”

With newly-formed organizations like the Canadian MPN Research Foundation, as well as others dedicated to helping those with serious cancers such as Heal Canada, patients and their loved ones have more resources than ever to help them navigate life with blood cancer. ♦

For more information on the foundation and to fund vital MPN research, visit cmpnrf.ca.

MPN Canadian
Research
Foundation

New Therapies Help Canadians Living with Hemophilia Lead Full, Active Lives



Dr. Man-Chiu Poon

MD, FRCPC Emeritus Professor & Clinical Professor of Medicine, Paediatrics & Oncology, Cumming School of Medicine, University of Calgary

Hemophilia is a hereditary disorder affecting approximately 3,000 Canadians of all ethnic origins in which blood doesn't clot normally due to a lack of the protein Factor VIII or Factor IX. Individuals living with hemophilia don't bleed more profusely or more quickly than other people; they bleed for a longer time.

Hemophilia is divided into type A (Factor VIII deficient) and type B (Factor IX deficient). Approximately 80 percent of cases in Canada are type A. Classified as severe, moderate, or mild, the most severe forms of hemophilia affect males almost exclusively. The greatest danger for those living with hemophilia is internal bleeding, which occurs in tissues, muscles, and joints — especially knees, ankles, and elbows.

"If not treated appropriately, these hemorrhages cause much pain and often lead to arthritis-related disabilities and problems with the muscle-skeletal system," explains Dr. Man-Chiu Poon, of the Southern Alberta Rare Blood and Bleeding Disorders Comprehensive Care Program at the University of Calgary and an internationally recognized researcher

in the area of hemophilia.

Dr. Poon has experienced the evolution of care for people with hemophilia over the past 45 years and witnessed the continual improvement of their quality of life and life expectancy. They now have many management options and he believes their future is bright with curative treatment being on the horizon.

Leading a full, active life with hemophilia

With new treatments becoming available frequently, most people with hemophilia can lead full, active lives. The basic treatment to stop or prevent bleeding related to hemophilia A and B is factor replacement therapy — the injection of Factor VIII and IX concentrates into the bloodstream. An innovative factor VIII replacement therapy approved by Health Canada in July leverages an extended half-life to help Canadians living with hemophilia A better manage bleeding episodes. There are also extended half-life products for those with hemophilia B.

"Whereas we previously would have had to provide many patients with treatments several times a week (some even daily), with the longer half-life we're able to reduce the number of treatments," explains Dr. Poon.

In Canada, medical services for the treatment of hemophilia and related conditions are provided at a comprehensive care clinic. ♦

Gavin Davidson

To discover more, visit hemophilia.ca.

DO YOU KNOW THE SIGNS OF A BLOOD CLOT?

An easy way to remember the **most common symptoms** is:



CHEST PAIN

A blood clot in the lung causes it to swell, resulting in sharp chest pain when breathing.



LIGHT-HEADNESS

A blood clot in the lung causes light-headedness or dizziness, especially if larger or multiple clots block blood flow to the lung.



OUT OF BREATH

A blood clot in the lung reduces the flow of oxygen throughout the body, which causes difficulty breathing.



TENDERNES IN THE LEG

A blood clot in the leg causes tenderness or cramping in the calf or behind the knee, as well as redness and warmth.



SWELLING IN THE LEG

A blood clot in the leg blocks blood flow to the veins that drain blood from the leg back to the heart. This causes the leg to swell.

IF YOU HAVE ANY OF THESE SYMPTOMS, GO SEE A DOCTOR RIGHT AWAY!

Read the full article online at healthinsight.ca.

Sponsored by



LIFE-SAVING STEM CELLS TREATS OVER 80 TYPES OF DISEASES

Learn how stem cells save lives at: www.progenics.ca

My Blood, My Health – a Simple Test Can Put You Ahead of the Game

As Canadians, we could say that hockey is in our blood. But hockey legends Paul Henderson and Kerry Fraser understand all too well that blood also holds clues to our health. A blood test in 2009 revealed that Henderson had chronic lymphocytic leukemia and in 2017 Fraser found out he had essential thrombocythemia, a rare blood cancer.

“Something didn’t feel right with my body and I had to make a call – thankfully I made the right one and called my doctor,” says Fraser, a broadcaster and former National Hockey League senior referee.

Fraser and Canada’s Sports Hall of Famer Henderson have teamed up with Heal Canada, a collaborative patient advocacy

and education organization, and Novartis Pharmaceuticals Canada Inc. to raise awareness about the need for Canadians to speak up when something doesn’t feel right with their bodies.

“A simple blood test could help you find out what’s going on with your body.”

Symptoms of blood cancers can be deceptive and can sometimes be mistaken for a bad cold or flu, or there may just be a general feeling of being unwell. The complete blood count (CBC) test can help detect an underlying condition.



Henderson celebrating the winning goal for Team Canada in the '72 Summit Series. Taken by Frank Lennon, the photo has been called “one of the 10 images that changed Canada.”

“A simple blood test could help you find out what’s going on with your body. It could be nothing, but if it isn’t, you need to form a solid game plan with your health team as soon as possible,” says Fraser. ♦

More information on how to play to win when it comes to deciphering clues to your health can be found at mybloodmyhealth.ca.

Canadian MPN Research Foundation Aims to Find a Cure for Progressive Blood Cancers

When someone says blood cancer, you may immediately think of leukemia, but there are many types of blood cancer that aren’t as well-known. For those living with myeloproliferative neoplasms (MPNs), these serious cancers are very real and often incurable.

MPNs are progressive blood cancers in which the bone marrow typically overproduces one or more types of blood cell. The three most common classical MPNs are polycythemia vera, essential thrombocythemia, and myelofibrosis.

With stem cell research and the discovery of key gene markers, there have been significant advances in the diagnosis, understanding, and treatment of MPNs, but there are still no known cures for most of these cancers.

The Canadian MPN Research Foundation is on a mission to change that. Founded in 2018 by Executive Director Cheryl Petruk, the organization has a single goal: to stimulate and fund original and ongoing research in pursuit of new treatments and eventually a cure for MPNs. Cheryl became an advocate for the MPN community when she began caring for her late husband.

The dedicated members of the board each have very personal and committed ties to the foundation’s mission. They seek to support MPN research projects in centres across Canada, including at the Elizabeth and Tony Comper MPN Program at Toronto’s Princess Margaret Cancer Centre, which is exploring novel treatment, models of care, and education strategies.



Dr. Vikas Gupta

Director, Elizabeth & Tony Comper MPN Program, Princess Margaret Cancer Centre
Professor, University of Toronto

“It’s unimaginably devastating to be diagnosed with an incurable blood cancer.”

“It’s unimaginably devastating to be diagnosed with an incurable blood cancer,” says Dr. Vikas Gupta, who leads the clinical research team. Patients with MPNs have a heavy symptom burden which affects their day-to-day life. Several of the complications related to MPNs such as thrombosis, are preventable. “That’s why we’re working so hard to make significant strides in our understanding and treatment of these progressive cancers,” says Dr. Gupta. “The funding we’ve received so far has helped us start our journey, but we have a long way to go. With the support from funding partners, we’ll continue to work hard towards our goal of finding a cure.”

With newly-formed organizations like the Canadian MPN Research Foundation, as well as others dedicated to helping those with serious cancers such as Heal Canada, patients and their loved ones have more resources than ever to help them navigate life with blood cancer. ♦

For more information on the foundation and to fund vital MPN research, visit cmpnrf.ca.

MPN Canadian
Research
Foundation